# Electronic Health Records & Health Information Infrastructures:
## Local, National, & Global

Don E. Detmer, MD, MA

**Governor's Electronic Health Record Task Force**

Richmond

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AMIA

# Don E. Detmer, MD MA

President & CEO,

**American Medical Informatics Association**;

Professor of Medical Education

**University of Virginia**

detmer@amia.org

detmer@virginia.edu

# American Medical Informatics Association

The National Professional
Organization of 3500 Informaticians

See www.amia.org

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# Overview

- Major Issues pushing IT
- How US EHRs & NHII got where they are
- Key Concepts & Visions
- Key Realities
- Opportunities

# Big Picture Diagnosis
## *The future just isn't what it used to be.*

- Health & its care is information intensive.
- The knowledge base is expanding rapidly.
  - Basic biology, clinical care, public health
- Aging & Chronic Illness requires informed patients & active disease management.
- Disease & our collective fate is global.
- Current systems perform too poorly.

# Health Care Systems are in Need of Fundamental Change.

Dx: Unsafe, costly, inefficient, inequitable ....

The current care systems cannot do the job.  Trying harder will not work. Changing systems of care will.

- IOM: Crossing the Quality Chasm, 2001

*Q:* The Biggest 2000-2005 Take-home Message on "What Isn't Working Well"?

*A:* The US Healthcare Non-system…

We need transformation with universal coverage for what works plus EHRs and a NHII.

# Google v.2005

- Love –            227m
- Sex –            105m
- Terrorism –       46m
- Life        –        600m
- Business –    1.2b
- Privacy -      2.02b

- Michael Jackson – 26m
- Britney Spears –        5.3m

- Electronic Health Record – 19m
- Electronic Medical Record - 16m
- NHII – 18.3m

# How EHRs & NHII Got Here.

## POLICY – 1989-2005

# Two Phases to USA Story Thus Far

- 1991-2001 – Computer-based Patient Record (EHRs)

- 2001- present – NHII – Washington phase

- PHASE III Beginning?

  2006- 2015 – Local, Regional, Global HII?

# Phase I: *"An Essential Technology for Health Care"*

1ˢᵗ edition:

1987-1991

Computer-based Patient Records

IOM (see http://www.nap.edu)

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# The Computer-based Patient Record: An Essential Technology for Health Care

- The 1991 Report
  - A newly conceived record, not a digital version of traditional medical record
  - Computer-based -- Put the focus on the record, not the computer
  - Data entry by relevant responsible person
  - Deal with confidentiality & security

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# Twelve Attributes of the Computer-based Patient Record

- The CPR has a problem list with status of each problem

- The CPR encourages health status & functional level measurement to promote outcomes assessment

- The CPR documents clinical rationale

# Twelve Attributes of the Computer-based Patient Record

- The CPR can link to other clinical records over time

- The CPR system protects confidentiality comprehensively

- The CPR is accessible on a timely basis to authorized individuals

# Twelve Attributes of the Computer-based Patient Record

- The CPR system allows selective retrieval and formatting

- The CPR system links to local & remote knowledge, literature, data-bases, & systems to aid decision making

- The CPR assists & guides clinical problem solving

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# Twelve Attributes of the Computer-based Patient Record

- The CPR supports data collection & storage with a defined vocabulary

- The CPR helps manage quality & cost of care

- The CPR is flexible & expandable to meet needs over time

# Electronic Medical Records

Initially

1)  EMRs sought to make medical diagnosis – Artificial Intelligence

2)  Run Administrative Functions like billing

3)  Then HELP (Utah) developed decision support

# EMR Development

- PACs systems for imaging – lots of memory

- Standards emerged to replace legacy systems & enhance interoperability – still underway

- Moore's Law

# The Computer-based Patient Record:

*An Essential Technology For Health Care*

- Set goal of 10 years for widespread implementation, e.g., 2001
- CPR Institute founded
  - Security Guidelines, etc.
  - Nicholas Davies Awards

# Without Confidentiality & Security Legislation the CPR was going nowhere.

# Response to IOM CPR Report

- USA -  American Medical Informatics Assn. / IBM / AHIMA / etc.
  - Pass Bennett Bill…HIPAA & work on Privacy Regulations
- England
  - Develop '*Information* for *Health*' Strategy for national EHRs
- Australia, New Zealand, Canada, Netherlands, Denmark
  - Develop  national EHR plans

# The Computer-based Patient Record: An Essential Technology for Health Care

- The 1997 Report
  - Same content as 1991 Report plus
  - USA Update - Tang / Hammond
  - European Update -  van Bemmel / van Ginneken / van der Lei – Netherlands
- Europe developed privacy laws post US Government legislation in 1970s
- US Approx. 7-15 years behind Europe

# The Economist Magazine ~ 1997

"The CPR Report of the Institute of Medicine changed the electronic medical record from the realm of "off-beat visionaries" to an "establishment-endorsed probability.""

# What was needed in USA?
Specific Federal Legislation for Confidentiality & Security… & then on to EHRs

## What we got?

- HIPAA's Administrative Simplification Privacy Regs

- Two – three years working on privacy regulations that still aren't quite right for research & care or personal identifiers
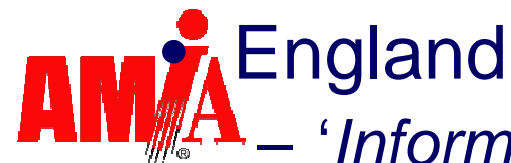
# USA NHI Strategy Policy '96:
## Nashville IAIMs Consortium /AMIA meeting

- Universal Access to Web & Health Resources
- Telemedicine & Tele-education
- CHRs
  - Hospital & Primary Care
  - Personal Health Records
  - Population Health Records
- Decision Support Systems
- Standards Development
- Confidentiality & Security
- Research, Education, & Development
- International Collaboration
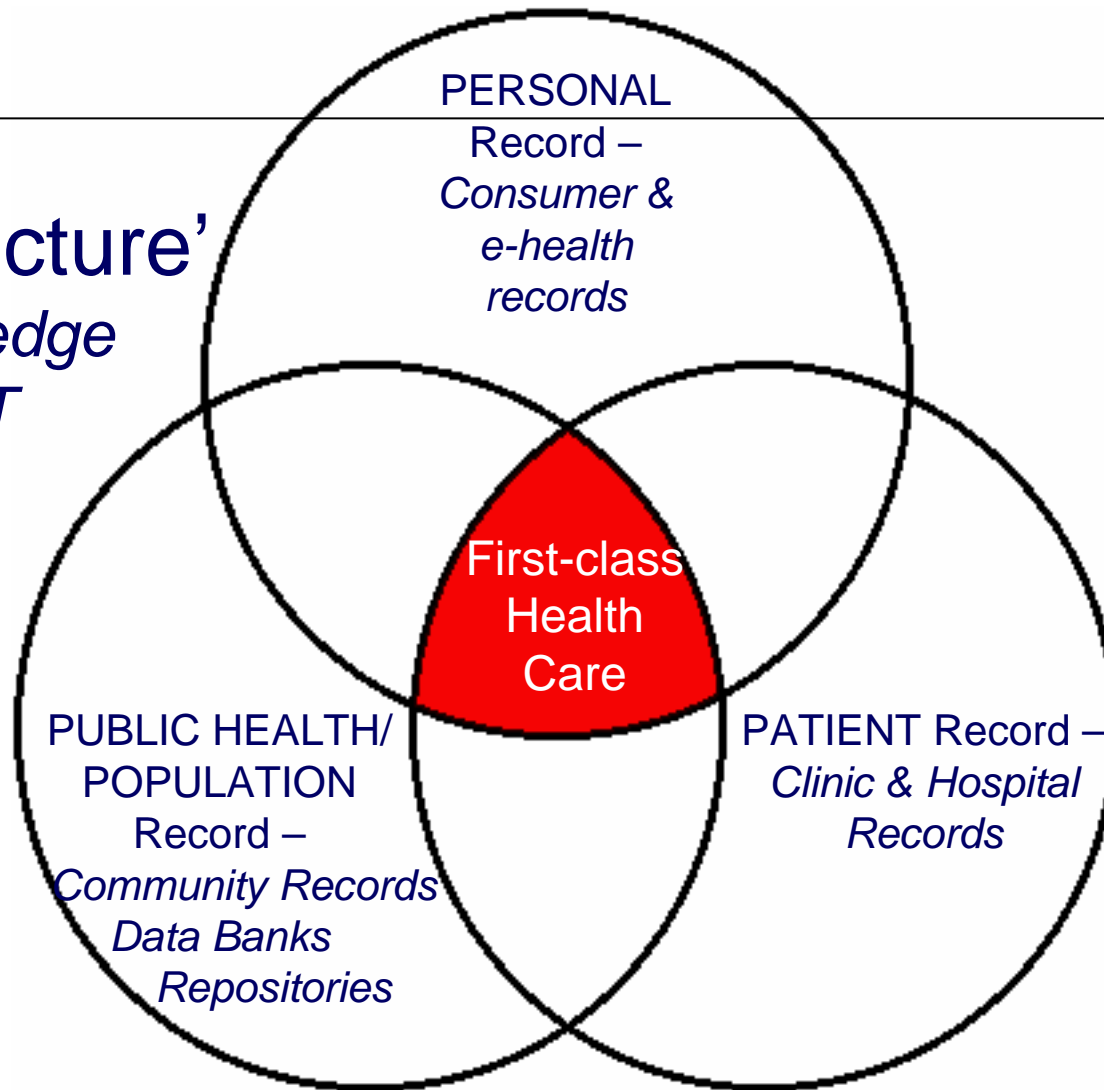
# Notable Activities

- USA
  - Health Insurance Portability & Accountability Act of 1997
    - Administrative Simplification for Standards incl. Privacy & Security; CPR Standards; Unique Identifiers
  - VA & DOD develop system-wide CPRs using IOM Report as planning template
  - NCVHS reorganizes into the government's National Health Information Policy Advisory Committee
    - **NHII Working Group** formed
- England
  - '*Information* for *Health*' process '95-'98

'Infostructure'
*Knowledge & IT*

PERSONAL Record – *Consumer & e-health records*

First-class Health Care

PUBLIC HEALTH/ POPULATION Record – *Community Records Data Banks Repositories*

PATIENT Record – *Clinic & Hospital Records*

Interlocking computer-based health records (3 EHRs) supported by knowledge & IT infrastructure – The E H R NCVHS  NHII Working Group

# IT Relevant IOM / NRC Reports

- The Computer-based Patient Record        1991 & 1997
- Health Data in the Information Age        1994
- Telemedicine        1995
- For the Record        1997
- Trust in Cyberspace        1999
- Networking Health        2000
- Key Capabilities of an Electronic Health
    Record System        2003

# IOM Quality/Safety Reports

- To Err is Human                                            1999
- Crossing the Quality Chasm                          2001
- Leadership by Example                                  2002
- Fostering Rapid Advances in Health Care   2002
- Health Professions Education:
  - A Bridge to Quality                                      2003
- Chasm Summit                                              2004
- Patient Safety: Achieving a New Standard
  - of Care                                                        2004
- Quality through Collaboration: the Future
  - of Rural Care                                              2005

# Six Rules for the Health Care Delivery System

- Safe
- Effective
- Person/Patient-Centered
- Timely
- Efficient
- Equitable

- *IOM:Crossing the Quality Chasm*, 2001
  (see www.nap.edu)

# The Message for Today

**"In the absence of a national commitment and financial support to build a national health information infrastructure, the committee believes that progress on quality improvement will be painfully slow**."
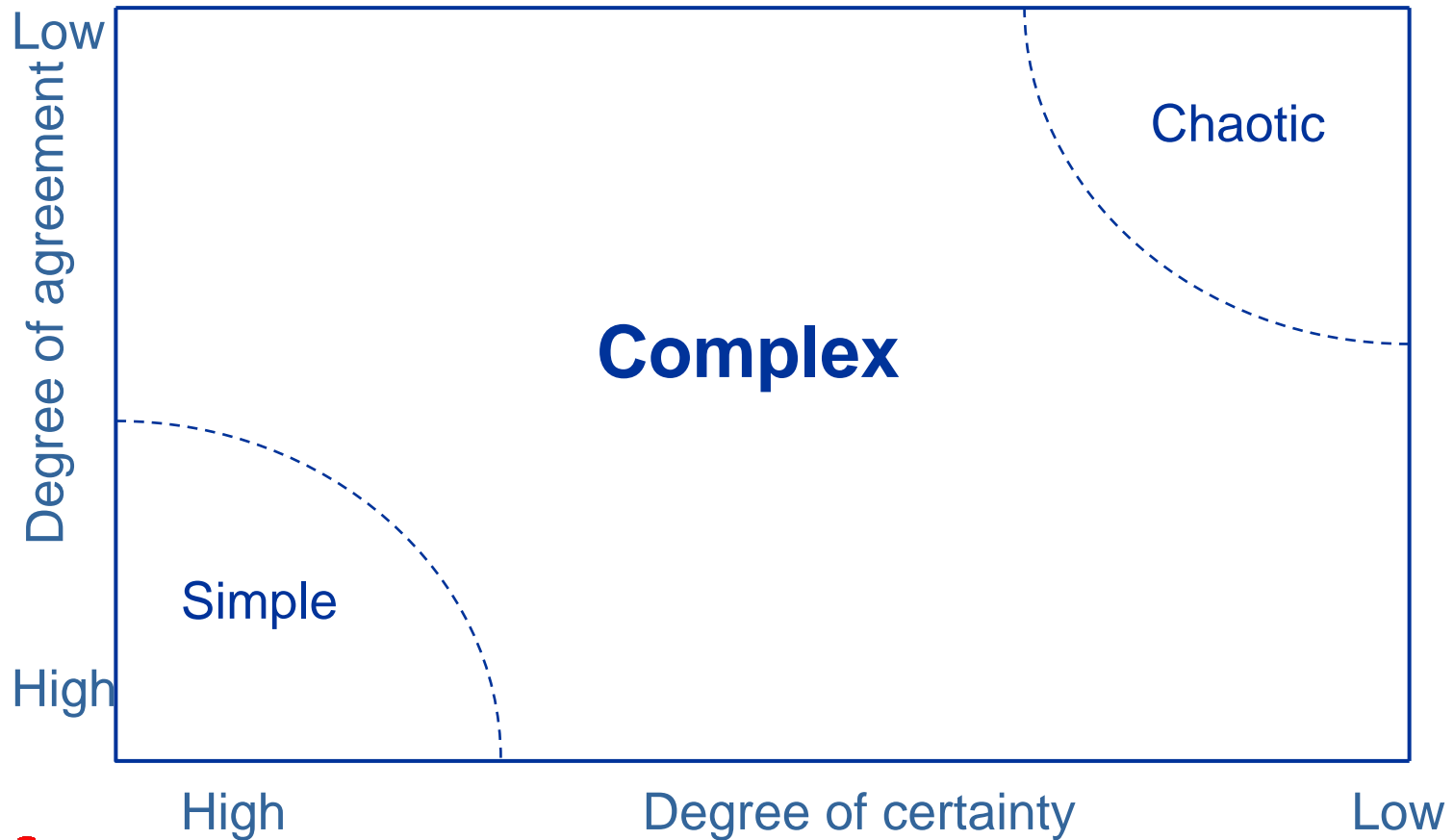
   – *Crossing the Quality Chasm: A New Health System for the 21st Century,* IOM, 2001

# Evidence?

- England investing billions in NHS NHII.
- Veteran's Administration performance blows past NCQA quality criteria.
- Other examples…Kaiser, Partners (Good Computer Clinician Order Entry Systems reduce 80% errors)
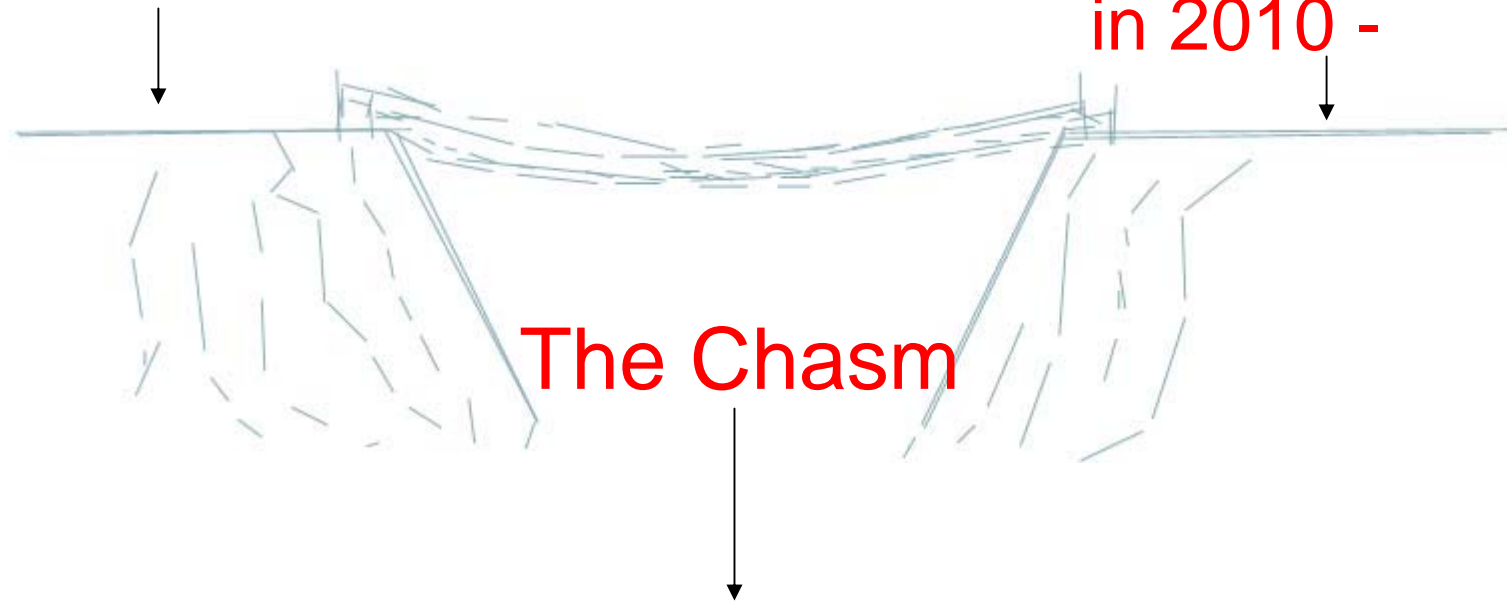
# Health Care Systems are very Complex.

Healthcare in year 2000.

NHII – The Bridge to Cross the Chasm

Healthcare with 'paperless Healthcare' in 2010 -

The Chasm

Mantra: We will use IT to help transform our system(s)!

# By '02 & '03 NHII is moving! Why?

- IOM Quality Series
- IOM Support of EHRs & NHII
- **New Advocacy & Support Groups**
- +/- More & better evidence of how IT can improve healthcare safety & quality

# More New Relevant Organizations

- Markle - Connecting for Health
  - http://www.connectingforhealth.org/
- National Alliance for Health Information Technology
  - http://www.ihealthcoalition.org/ethics/ethics.html
- E-health Initiative
- E-health Institute
- E-health International
  - http://www.ehealthinternational.org/index7.php

# E H R   Collaborative

- American Health Information Management Association (AHIMA)

- American Medical Association (AMA)

- American Medical Informatics Association (AMIA)

- College of Healthcare Information Management Executives (CHIME)

- eHealth Initiative(eHI)

- Healthcare Information and Management Systems Society (HIMSS)

- National Alliance for Health Information Technology (NAHIT)

# Foundation Initiatives

- Commonwealth Fund
- RWJ
- Picker
- Nuffield (UK)
- Others

**Two Questions on Hill**
Q 1)  "What Isn't Working Well"?
Q 2) "What could help?"

A 1) "US Healthcare System"
A 2) "Healthcare IT"

Science is a fascinating subject. One can get such a wholesome return of conjectures from such a trifling investment of fact.

- Mark Twain

# Hitting a Target
# in Complex Systems

- In command & control models, Newton's laws of motion can calculate how to do so
  - Works well for inanimate materials like a rock.
- It fails if you throw a bird!
  - A bird is a complex adaptive system.
- True despite both being subject to the same laws of physics
  - adapted from Jake Chapman

# Leading Change in Complex Adaptive Systems

- Set simple rules & minimum specifications
- Create conditions for system to evolve over time
- Create space for creativity & local actions within the system
- This is "Self-organization."

- Complex Adaptive Systems Theory

# Complex Adaptive Systems: Birds, Herds, Schools

Observe 3 simple rules:

- Move to the center of the group.

- Keep up with the group.

- Don't hit anyone.

- Reynolds 1987

# Essential Elements of 21st Century Health Care System

- Widespread use of evidence-based medicine

- Robust information infrastructure

- Aligned reimbursement incentives & regulatory requirements

- Workforce skilled in evidence-based medicine, IT, & process improvement
  - *Crossing the Quality Chasm, 2001*

# Evidence suggests:

**Better informed patients are:**

- Less anxious

- Treatment starts earlier

- More satisfied & litigate less

- Follow advice better

- Lower risk interventions are selected

- Healthcare costs drop through more self-management & a more efficient use of resources

        - Detmer et al:

    "The Informed Patient" Study - 2003

# e-Health Definition
## Ex: Clicks & Mortar

- Cleveland Clinic – C. Martin Harris
  - My Chart, My Consult, My Monitoring
- CareGroup Health System – John Halamka
  - PatientSite
- Palo Alto Clinic – Paul Tang
- Others

# "I think I know the problem, please help me manage it*."

## 'Just-in-time'

## knowledge service

## with strong decision support

Me* = patient, non-professional caregiver, health professional, informaticist, policy wonk, payer, business leader, etc.

# Evidence-based Adaptive Decision-support Systems

- Evidence-based
  - Locally generated & from literature
- Decision-support systems/templates with 'just-in-time' knowledge service at 'point of care'
- Adaptive – continuously studied & improved against care delivered & patient's outcomes
  - Sim, Gorman, Greenes et al, JAMIA 2001
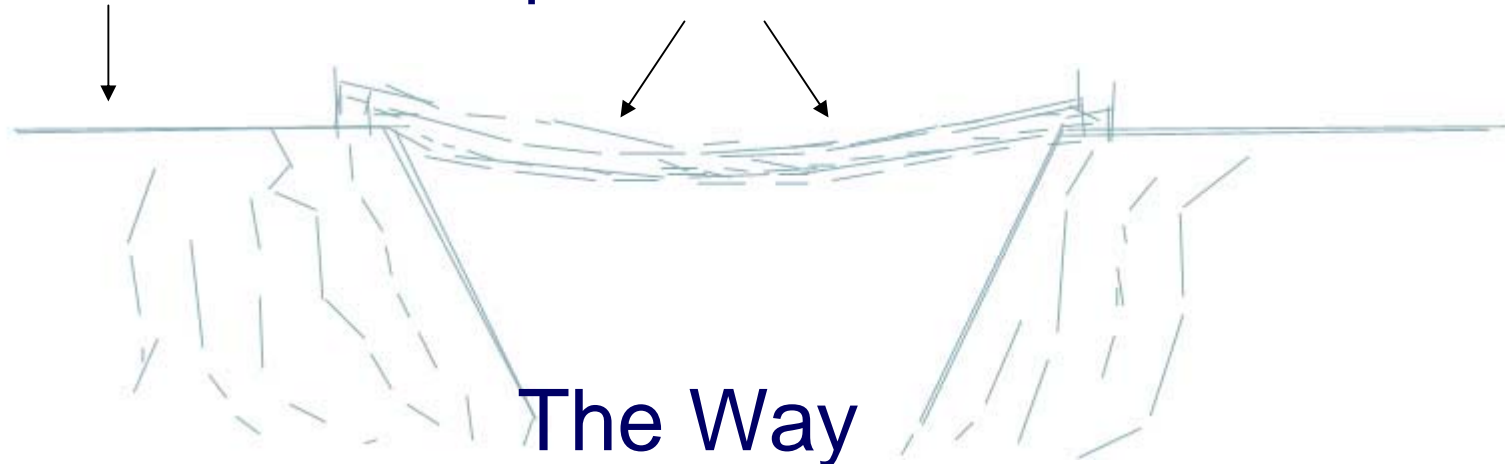
- Examples:  IHC Utah
  - No. New England CV Group

# Life in the Complexity Zone
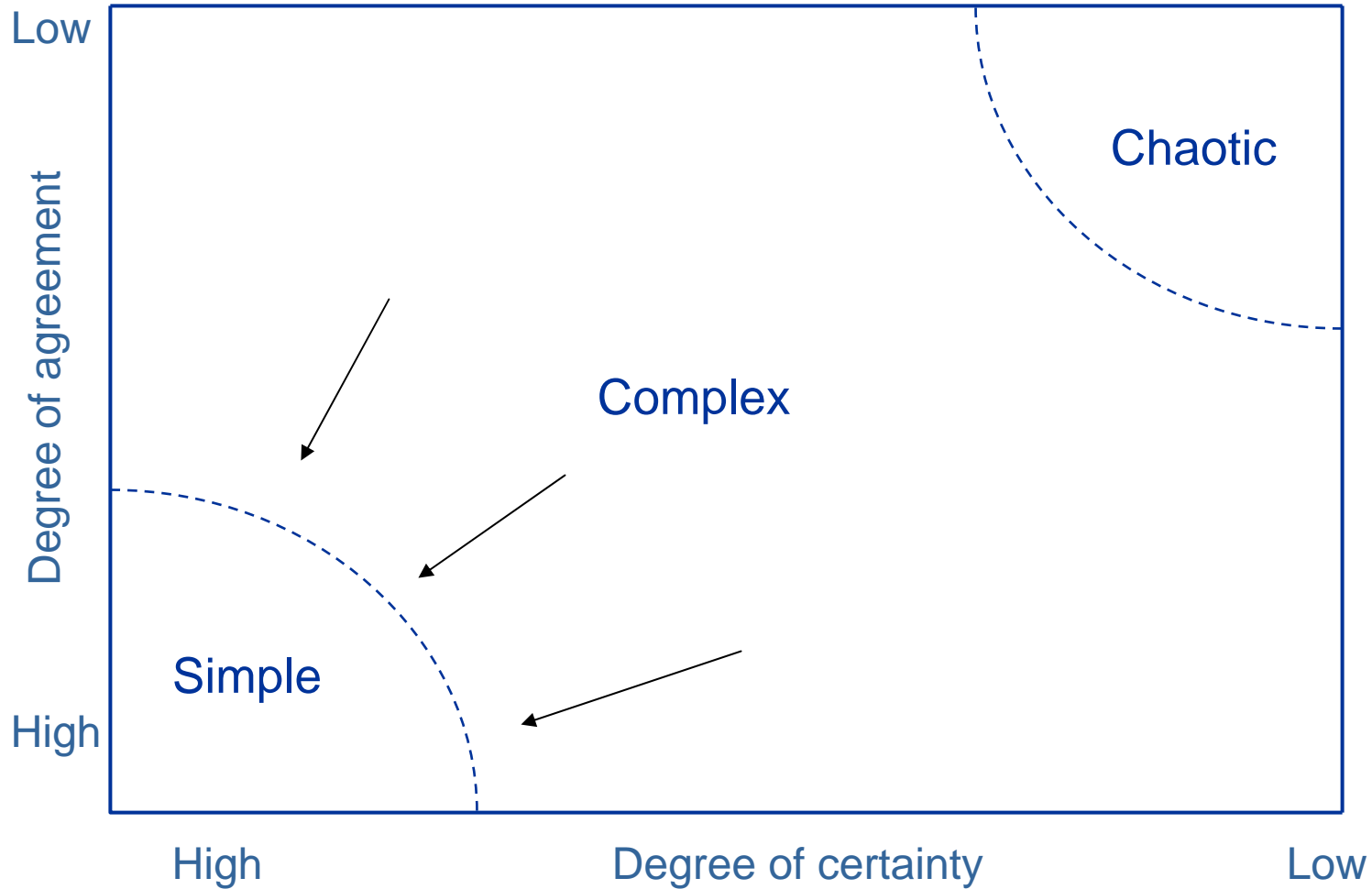
The year 2000

Self-organization in Complex Adaptive Systems with 'Paperless' Healthcare:

2020 -

The Way Across The Chasm

# Presidential Support

- Clinton – 1990s  - Privacy for Medical Records

- Bush – 2004 – Electronic Health Records
  - State of the Union Address
  - Radio Address
  - NHII Office & $$
  - Commission on Systemic Interoperability

# Global Leaders

- England/Wales NHS Information for Health
- Australia
- New Zealand
- Canada
- Netherlands
- Denmark

# Global & National HII **Standards**

- Easy Relevant Secure Data Exchange among all key players

  - Connected
  - Compatible
  - Interoperable

# Role of Government*

- "Rules of the Road"
  - Data Standards, Laws & Regulations
- "Building the highway"
  - Public – private partnership for secure data exchange
- "Use of the highway" - money
  - Private sector with government
  
  help for access to capital

* Paul Tang: NHII03 meeting July03

**2004**:  Regional Health Information Organization (RHIOs)


**2005:** States Enter the Scene

# Tensions: Reconciling Proprietary Innovation & Systems Compatibility

- Genomics
  - Intellectual Property (patents/licenses) v. Common Domain
- IT/ Telecommunications
  - Proprietary Systems v. IT (including Health) Commons Domain

# Values Expressed in Policy & Strategy

## Healthy Individuals
## Healthy Communities

Support personal, community & professional health decisions using the best available knowledge & support.

Sometimes your best isn't enough.  Sometimes you must just do what is needed to get the job done.

-Winston Churchill

# The Big Vision for Health Communications - "Information *for* Health"

- A Global Health Information Infrastructure is …'the set of values, systems, standards, applications, technologies, & laws that support **all** facets of individual health, health care, and public health.'

  – Adapted from NCVHS 2000

# Privacy v. Research Today

## Life after the
## final Privacy Rule of HIPAA

# The Promise of the final Privacy Rule

The modifications in the final Rule are said to remove "obstacles that may have interfered with research activities that form the basis of advancements in medical technology & provide greater understanding of disease…." And further, "research is the key to the continued availability of high quality health care.  The modifications remove potential barriers to research."  (67 F.R. 53259, 53260)

*(what)* the Privacy Rule requires of either an institutional review board (IRB) or Privacy Board (PB) with respect to the creation of databases is enormous (authorizations, waivers, limited data sets, data use agreements), yet the gain in subject privacy and confidentiality is

virtually non-existent.

# April 2003 AAMC Survey Conclusions

- Essential biomedical, epidemiological, & health services research is curtailed.

- The provision of health care is harmed.

Ehringhaus, AAMC, Nov 03

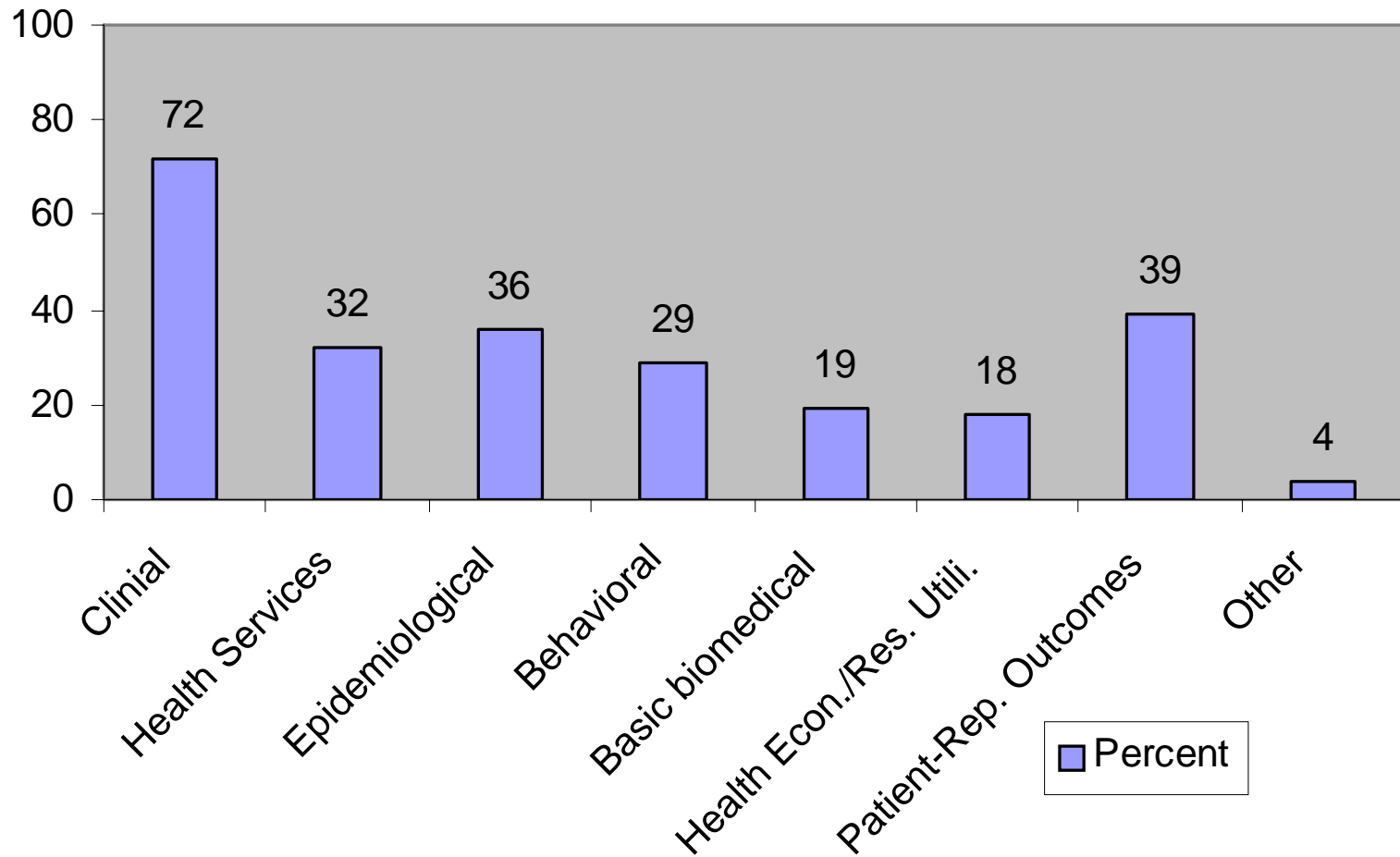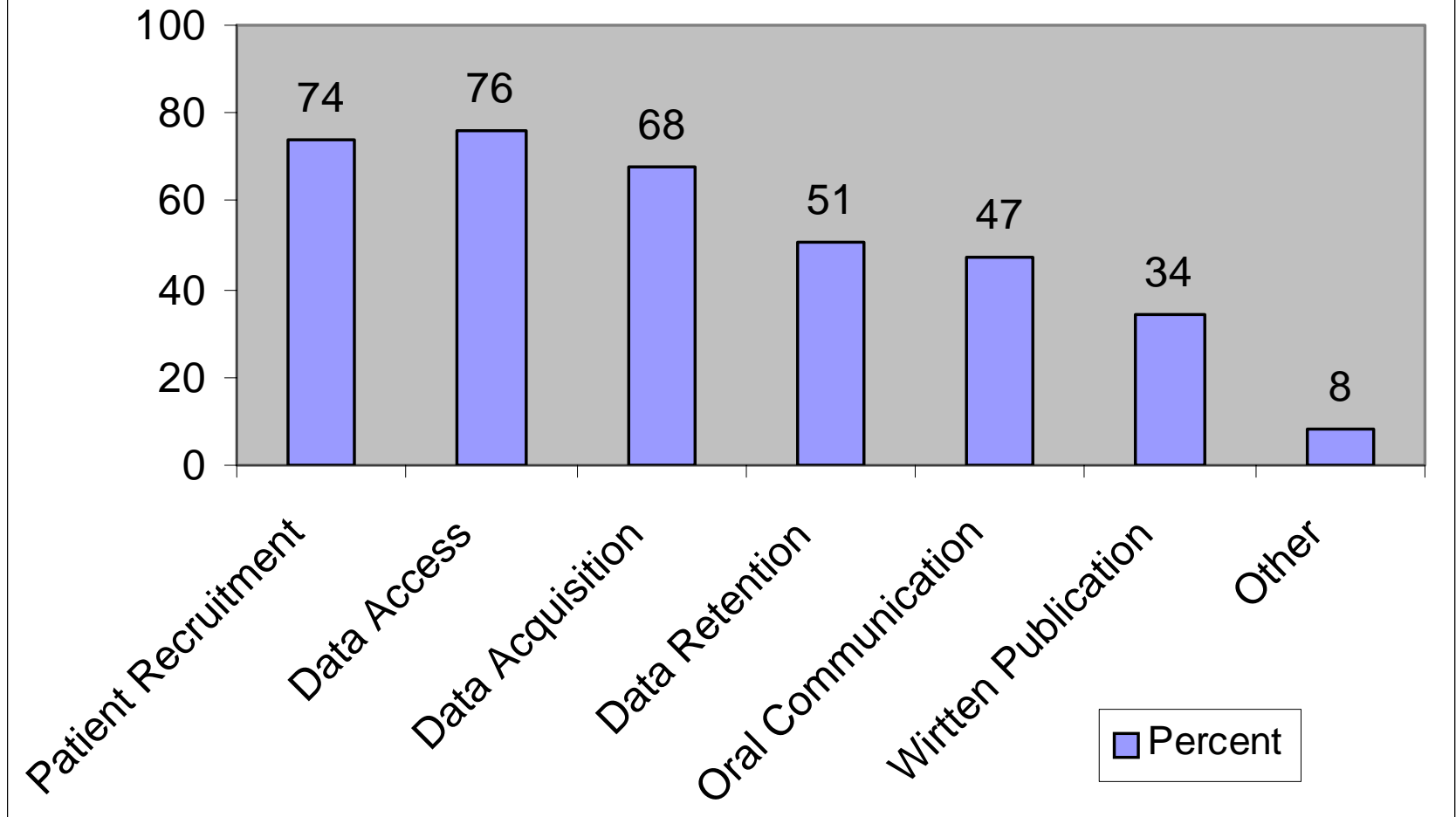# Chart 1. Types of Research Affected by HIPAA



n = 331                Ehringhaus, AAMC, Nov 03

Chart 2. Research Functions Affected by HIPAA

Ehringhaus, AAMC, Nov 03

# Final Privacy Rule:
# Four Changes Needed (I)

- **Accounting for Disclosures**
  - Required for fewer than 50 subjects
    - Rec: Eliminate
- **Authorizations & Waivers**
    - Rec: Eliminate since redundant
- **De-Identification Standard**
  - Too stringent
    - Rec: Simplify

Ehringhaus, AAMC, Nov 03